Technology-Mediated Social Participation in Health and Healthcare

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Introduction

Since 2003, the National Institutes of Health has been tracking online use of health information through the administration of its biennial Health Information National Trends Survey, or *HINTS*.[1] Data from this and other surveys have shown a steady rise in Internet penetration among public consumers from roughly 45% at the beginning of the decade to 75% at its conclusion.[2] In all of these surveys roughly half of the online population reported having looked for health information – either for themselves or for a loved one – in the previous 12 months.[3] By the end of the decade an estimated 90 million Americans had reportedly gone online in the previous year to look for health information in one form or another.

Other, more social uses of the Internet in the service of health or health care have been on the rise. By 2008 the percentage of online Americans who reported being able to communicate with their healthcare providers through email doubled from a meager 7% of the online population in 2003[4] to 15% in 2008.[2] That percentage is expected to increase steadily as funds from the American Recovery and Reinvestment Act of 2009 stimulate adoption of electronic health records by physicians and hospitals.[5] In fact, the use of asynchronous messaging capabilities within the electronic health record has already been credited with the introduction of significant cost savings and medical efficiencies within a large managed care system.[6]

The introduction of patient portals as access points to personalized health information integrated with an underlying system of fully interoperable electronic medical records is another way in which health information technology is expected to increase public participation in the years to come.[7] Indeed, the deployment of electronic health records to promote *patient engagement* is an explicit goal within the Department of Health and Human Services' Office of the National Coordinator for Certification of Health Information Technology.[8] HINTS 2008 began tracking the public's awareness of electronic health records in general and the public's willingness to share their personal data for purposes of research as in particular. Results showed a modicum of awareness for physicians' use of electronic health records currently (55.6%), but a substantive predilection to access personal health data electronically if it were available (85.6% said this was important) and an expressed willingness to share personal data with scientists in a participative way (71.9% agreed in concept) if safeguards for privacy were ensured.

Finally, in terms of social media usage, HINTS 2008 began tracking respondents' use of social networking sites, such as Facebook® and Linked-in®. Penetration rates for these technologies hovered around 23% overall in the 2008 survey; however, analyses uncovered a strong inverse relationship between social media use and age, with a penetration rate up to 74% for the online segment aged 18-24 years. According to these analyses, digital citizens in the youngest age range within the survey were estimated

to be 47.85% (95% CI =27.92 -82.00) *more likely* to engage in social media sites than those in the oldest range (65+) when controlling for other sociodemographic factors.[9] The use of social media in the service of health communication is likely to rise as usage patterns increase across age groups in the future.

Linking Technology-mediated Social Participation to National Goals

The stimulative passage of the Health Information Technology for Economic and Clinical Health (HITECH) portion of the American Recovery and Reinvestment Act of 2009 is merely the latest salvo in a decade-long effort to empower physicians, public health workers, and consumers with the reliable and accessible data possible to improve the nation's health.[10] One of the more seminal documents in this arena was a 2001 report from the National Committee on Vital and Health Statistics titled "*Information for Health: A Strategy for Building the National Health Information Infrastructure.*"[11] Released in the shadow of 9-11, when "connecting the dots" between information sources dominated the attention of policy makers, this founding blueprint promoted a *national health information infrastructure (NHII, later rebranded as a national health information network, or NHIN)* based on network access to reliable data interconnected from three spheres. The spheres included: (a) a *clinical health* domain in which the best medical science would be combined in reliable ways with up-to-date data on patients' conditions and histories; (b) a *personal health* domain in which high quality medical information would also be made available to patients and their families for in the service of healthy living (and not just disease management); and (c) a *population health* domain in which data about individual experience with disease or trauma could be mined to address issues of subpopulation inequity within the public health sphere.

Inherent in the National Committee's articulated strategy was the explicit role of data as the new currency within the system. The proposal that heretofore disparate data systems be made to interoperate for the public's good was audacious and transformational, in the same way that discussions over Web 2.0 were transformational in their implications for new economy and new societal structures. It could be argued that national discussions of "Health 2.0" could in fact be attributed to the same zeitgeist the produced the 2001 national blueprint. This is especially true when taking into account the principles of Health 2.0 articulated in several international conferences; namely, that the Web must evolve to enable true participation by constituent parties, that it must enable a new sense of collective intelligence as information is combined in transparent ways for all parties to examine, and that it must rely on data as the new "Intel inside" for the new system.[12]

Figure 1 offers a blueprint of opportunity for investigating the possible contributions from technology-mediated social interaction in health. At the center of the figure lies the three-sphere diagram introduced by the National Committee on Vital and Health Statistics. Around the periphery of the diagram are examples of technology-mediated social interaction in health as enabled by current instantiations of Web technology. The list is not intended to be exhaustive; rather it is intended to give a feel for the new areas of technology development being monitored by the federal health agencies. For illustrative purposes, a brief synopsis of each follows.

- **Public transparency in the context of quality improvement.** At the beginning of the last decade, the Institute of Medicine released its landmark report on improving the healthcare system titled "Crossing the Quality Chasm: A New Health System for the 21st Century."[13] This landmark report altered the conversation on health system design by emphasizing the ideas of human-systems integration as a way of eliminating medical error in clinical, outpatient, and home settings; and to orient reform of the healthcare system to goals of safety, effectiveness, efficiency, timeliness, patient-centeredness, and equity.[14] A central tenet in the report's recommendations is that the healthcare system must base its decisions on unobstructed access to data.

  RESEARCH NEEDS: Questions remain as to which levels of these highly sensitive patient data should be made accessible to the various stakeholder communities responsible for protecting the public's health. The dashboard widget presented in the top left of Figure 1 represents one example of how a state (in this case, Wisconsin) is using a top-line report of health systems data as a report card to the public in an effort to promote system improvement and accountability.

- **Physician participation.** The physician community, which has become increasingly more specialized and dependent on a tsunami of biomedical research data, is struggling to engage in community paradigm that will help protect the high standards of medicine's professional societies while making its decisions transparent to the lay public.[15] The American Medical Association's *Facebook* page to the left of Figure 1 is just one example of how the medical community is adapting to an online, participative world.

  RESEARCH NEEDS: Burning questions exist on how the community as a whole will be able to adapt to the expanding deluge of biomedical evidence data, in a domain of practice that must adhere to the strictest of for healthcare delivery.

- **Disease breakout maps, infodemiology.** One the more provocative consequences of the Web 2.0 revolution is the ability to identify reports of disease outbreak, environmental exposure, and other precursors to health problems quickly by exploiting the power of computer-mediated information searches, user-volunteered input, and remote sensors. As Gunther Eysenbach explained in his proposal to the medical Internet research community, this development could create a new era of "infodemiology" to complement more traditional methods of epidemiology in identifying the etiology and sequelae of disease.[16]

  RESEARCH NEEDS: Research questions abound on how to collect and report these data in ways that are scientifically based and that do not create panic within the general citizenry (e.g., the irresponsible reporting of illusory disease clusters a perennial bane of effective health communication.

- **Communities of health.** More and more it is becoming apparent that true public health will only emerge as the result of joint participation between scientists, trained health practitioners, the public, and policy makers. The five-decade old battle against the market dominance of the Tobacco Industry is just one example of what it has take for public health practitioners, physicians, scientists, policy makers, and public advocates to work together in creating environments that are smoke-free and healthy. A transparent and participative access to population health data should empower communities to organize themselves in ways that improve the living conditions for their members.

  RESEARCH NEEDS: James Surowiecki's provocative treatise on the "Wisdom of Crowds" was predicated on observations gleaned from social psychology that aggregate thinking can be superior to individual thinking under a highly specific set of identified boundary conditions.[17] Otherwise, the collective thinking of crowds becomes an inaccurate and sometimes dangerous manifestation of groupthink, collective oppression, or polarizing opinion making. Research is needed to translate social psychological research into reliable tools for improving community capacity.

- **User-augmented reality.** One of the more promising paths for turning data from the biomedical and population health spheres into usable information for the public is through access to health-enhancing information at the point of decision making. This type of personalized channeling of collective information may certainly be relevant to the medical decision process as embodied by the promise of *personal health records*, but it could also be channeled into the "Just in Time" decision support made available through mobile applications. Dietary reviews of restaurants, health enthusiasts' reviews of the built environment, and user-generated cues for navigating the help system can help embed instrumental support into the fabric of everyday living.[18]

  RESEARCH NEEDS: Just as the usability path for GPS-based technologies took years of refinement to enable real-time usage while driving, the usability path for consumer-oriented mobile technologies must be similarly scoped to protect consumer health and interest. The roles of multiple agencies such as the Food and Drug Administration, the National Institute on Standards and Technology, the Centers for Disease Control and Prevention, and the National Institutes of Health must be investigated in order to drive solutions that are protective of consumer well-being.

- **Patient participation sites.** In contrast to the traditional top-down view of health as an outcome guaranteed only by work championed within the biomedical sector, Web services such as those offered by *Google Health*, *Microsoft Health Vault*, and *Patients Like Me* illustrate what happens when the private sector courts direct participation by consumers through social media. Intriguingly, these types of new collaborations seem to be using the market to accelerate

progress in biomedical discovery, while bypassing the bureaucratic logjams of institutional review boards, HIPAA, and other administrative protocol.

RESEARCH NEEDS: It is perhaps in this area that concerns over commercial ulterior motives and public protectionism come into greatest conflict. Delicate research will be needed to balance the needs of science, of big business, and of patients to ensure that all participation is informed and consensual. A new regulatory system may need to be sure that the seeds we allow to grow today do not turn into the economic meltdown of tomorrow.

Figure 1. Illustrative opportunities expressed in terms of the National Health Information Network.
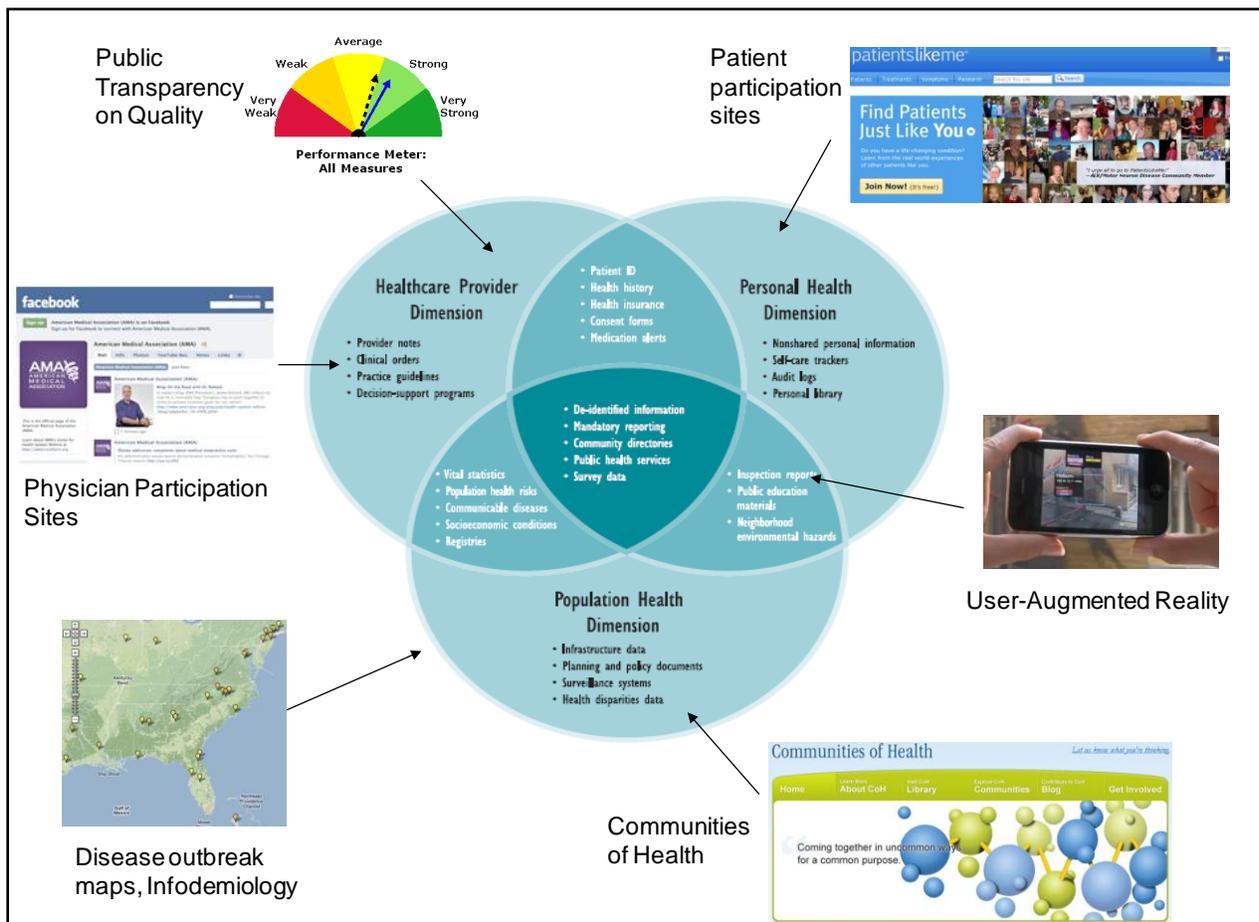
References

1. Nelson DE, Kreps GL, Hesse BW, et al. The Health Information National Trends Survey (HINTS): development, design, and dissemination. *J Health Commun.* Sep-Oct 2004;9(5):443-460; discussion 481-444.
2. Hesse BW, Moser RP, Finney Rutten LJ. Patient engagement and its implications for healthcare practitioners. *New England Journal of Medicine.* in press.

3.   Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med.* Dec 12-26 2005;165(22):2618-2624.

4.   Beckjord EB, Finney Rutten LJ, Squiers L, et al. Use of the internet to communicate with health care providers in the United States: estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *J Med Internet Res.* 2007;9(3):e20.

5.   Blumenthal D. Stimulating the adoption of health information technology. *N Engl J Med.* Apr 9 2009;360(15):1477-1479.

6.   Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. *Health Aff (Millwood).* Mar-Apr 2009;28(2):323-333.

7.   Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. *BMC Med Inform Decis Mak.* 2008;8:45.

8.   Meaningful Use Workgroup to the Health IT Policy Committee. *Meaningful Use: A Definition.* Washington, DC: Department of Health and Human Services; June 16, 2009 2009.

9.   Chou WY, Hunt YM, Beckjord EB, Moser RP, Hesse BW. Social media use in the United States: implications for health communication. *J Med Internet Res.* 2009;11(4):e48.

10.   Blumenthal D, Glaser JP. Information technology comes to medicine. *N Engl J Med.* Jun 14 2007;356(24):2527-2534.

11.   National Committee on Vital and Health Statistics. *Information for Health: A Strategy for building the National Health Information Infrastructure.* Washington, DC: U.S. Department of Health and Human Services;2001.

12.   Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. *J Med Internet Res.* 2008;10(3):e22.

13.   Institute of Medicine (U.S.). Committee on Quality of Health Care in America. *Crossing the quality chasm : a new health system for the 21st century*. Washington, D.C.: National Academy Press; 2001.

14.   Hesse BW, Shneiderman B. eHealth research from the user's perspective. *Am J Prev Med.* May 2007;32(5 Suppl):S97-103.

15.   Hesse BW. Harnessing the power of an intelligent health environment in cancer control. *Stud Health Technol Inform.* 2005;118:159-176.

16.   Eysenbach G. Infodemiology: tracking flu-related searches on the web for syndromic surveillance. *AMIA Annu Symp Proc.* 2006:244-248.

17.   Surowiecki J. *The wisdom of crowds : why the many are smarter than the few and how collective wisdom shapes business, economies, societies, and nations*. 1st ed. New York: Doubleday :; 2004.

18.   Boutin-Foster C. Getting to the heart of social support: a qualitative analysis of the types of instrumental support that are most helpful in motivating cardiac risk factor modification. *Heart Lung.* Jan-Feb 2005;34(1):22-29.